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Heneage, Celia, Morris, Di and Dhanjal, Kuljinder

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**Nothing About Us Without Us: Combining Professional Knowledge
with Service User Experience in Training about Mental Health and Learning Disabilities**

Celia Heneage¹, Di Morris², Kuljinder Dhanjal³

¹ Canterbury Christchurch University and Sussex Partnership Trust

² Canterbury Christchurch University

³ Sussex Partnership Trust

“Nothing About Us Without Us”¹: Combining Professional Knowledge with Service User Experience in Training About Mental Health and Learning Disabilities

Celia Heneage, Di Morris, Kuljinder Dhanjal

Abstract

Recent policy documents relating to people with learning disabilities have proposed that they be more fully included in generic mental health care provision. In practice such inclusion has been slow to proceed, hampered by factors which appear to include lack of knowledge and confidence on the part of generic mental health practitioners. Policy documents have also recommended training of practitioners by people with learning disabilities, which has been found to impact positively on confidence and attitudes. This study reports on a training session delivered to ‘Improving Access to Psychological Therapies’ practitioners by a service user with learning disabilities who has accessed mental health services, together with a clinical psychologist and an honorary assistant psychologist. The practitioners were asked to rate their knowledge about and confidence in working with people with learning disabilities before and after the training. Participants rated themselves as having significantly greater knowledge and confidence following the training, and many of the qualitative reasons given for these changes mentioned the contribution of the service user. This paper includes details of her particular contribution to the training, together with her reflections on the experience of joint training, given in an interview with the assistant psychologist. It is concluded that joint training needs to be developed and its impact further researched.

Key words: Learning Disabilities, Mental Health, Training, Service User.

Introduction

People with learning disabilities have often needed to find ways of coping with difficult circumstances, societal attitudes and inadequate service provision. However, in recent years policies affecting them have undergone significant change. The Department of Health (DoH)’s publications “Valuing People” (DoH 2001) and “Valuing People Now” (DoH 2009a) have acknowledged past inadequacies and aimed to set new directions which rectify inequalities and propose radically different ways of addressing the needs of this group of people. The documents focus on the four principles of rights, independence, choice and inclusion into the wider community, and also propose that the voices of people with learning disabilities themselves are increasingly taken account of.

One significant target of these documents has been the area of health, including mental health, with the proposal that people with learning disabilities gain access to generic mental health services. Such services now include the government’s ‘Improving Access to Psychological Therapies’ (IAPT) initiative (Department of Health 2008) which focuses particularly on the provision of support to people suffering from anxiety and depression. There is useful documentation to support the extension of generic mental health services to people with learning disabilities. The National Service Framework (NSF) for Mental Health (Department of Health 1999) has a ‘traffic light’ system to assess local performance in implementing its recommendations in which a green light is indicative of optimum

¹ “Nothing about us without us” was the title of a document by the Service Users Advisory Forum (subsequently the National Forum for People with Learning Disabilities) which informed the ‘Valuing People’ white paper (DoH 2001)

performance. In 2004 a “Green Light Toolkit” was specifically produced to demonstrate features of good services for people with mental health and learning disabilities and to help local areas to assess their own performance in this respect (Foundation for People with Learning Disabilities 2004). The national IAPT services have produced a ‘Positive Practice Guideline’ clarifying how their provision can be tailored to the needs of people with learning disabilities (Department of Health 2009b).

In practice it seems to be taking time to implement these changes and recommendations (Reid-Galloway and Darton 2007, MIND website), and it is worth considering some of the issues which may make it difficult. People with learning disabilities currently most commonly receive support from teams with specialist expertise (Bouras and Holt 2004), and there is a need to consider how such expertise can be shared more widely. Practitioners in generic mental health services may lack knowledge of documents specifically relating to people with learning disabilities and awareness of the imperative to include them. Additionally they may have feelings of uncertainty and fear about working with a group of people with whom they are unfamiliar (McConkey and Truesdale 2000). There would appear to be a clear need to find optimal ways of offering training and support which impart appropriate knowledge and impact on feelings of fear and potential prejudice.

Studies have indicated that direct contact with people with learning disabilities can be an effective way of allaying anxieties and imparting confidence. For example Murray and Chambers (1991) noted improvements in the attitudes of undergraduate nurses following their learning disability placements, and Slevin and Sines (1996) found that nurses who had higher contact with people with learning disabilities had more positive attitudes than those who had had less contact. Eichinger (1991) found that special education students felt that the direct contact with people with learning disabilities had been the most important feature of their multi-faceted learning experience, and that their attitudes had significantly improved following such contact. Such work resonates with the more established research area of ‘Intergroup Contact Theory’ (Allport 1954, Pettigrew and Tropp 2006) in which direct contact between different groups has been reliably found to reduce prejudice between such groups, particularly under the optimal conditions of equal status between the groups, common goals, a lack of competition between the groups and an authoritative sanction for the contact (Allport 1954).

People with learning disabilities are increasingly taking on roles as trainers, thus providing learners with direct contact experience in the actual teaching situation, and studies indicate that learners feel they have benefited from this learning. Hall and Hollins (1996) found statistically significant positive changes in the attitudes of medical students who had been trained by actors with learning disabilities. Tracy and Iacono (2008) found a significant positive change in the attitudes of medical students who had received training in communication from people with learning disabilities. Students reported feeling more comfortable with people with learning disabilities following the session, and noted that they valued them more as individuals.

Increasingly providers of training are encouraged to include service users in the provision of training (e.g. Health Professions Council 2009) and to find ways of including people with learning disabilities (Levin 2004). Gary Butler, a trainer with learning disabilities who is employed to teach medical students on an ongoing basis has co-written a book to support others who may undertake this role (Owen, Butler and Hollins 2004). Such involvement resonates with the recommendations of ‘Valuing People Now’ that people with learning disabilities should have a say in what happens in all aspects of their lives, including training (Department of Health 2009a).

Planning and Delivery of the Joint Training

In April 2009, one of the authors of the article (Celia Heneage) was asked to provide training about learning disabilities to the first cohort of IAPT Low Intensity Workers/Psychological Wellbeing Practitioners based at a university in the south of England, as part of their teaching on social inclusion and working with diversity. These workers are primarily graduates of different disciplines who have some experience of work in differing health or social care capacities. They provide time-limited psychological intervention, based on Cognitive Behaviour Therapy (CBT) principles, which includes provision of self-help materials, telephone advice and advice about employment. The invitation was extended because of CH's responsibilities for convening training about disabilities to trainee clinical psychologists at the university. In this role she is assisted by another author (DM), a member of SAGE (Service User Advisory Group of Experts) in the organisation, who has a learning disability and has used generic mental health services. DM was invited to jointly train the Psychological Wellbeing Practitioners.

In planning the training, information was solicited from one of the course staff about the IAPT curriculum and the needs of the Psychological Wellbeing Practitioners, and the cohort of practitioners were also given a questionnaire to ask them what they felt they needed to know about the area. Their principal requests were for general information about learning disabilities and ways to adapt CBT to meet the needs of this group of people. CH also considered issues raised in the IAPT "Learning Disabilities: Positive Practice Guide" (Department of Health 2009b), and both trainers were mindful of the content of their introductory session for trainee clinical psychologists, which is based on recommendations from the British Psychological Society (British Psychological Society 2005). This led to the consideration of four key questions:

1. What is a learning disability?
2. What emotional difficulties might people with learning disabilities experience particularly?
3. How can CBT be adapted to meet the needs of people with learning disabilities?
4. What information is available about people with learning disabilities and employment?

It was decided that the two trainers would answer the first two questions in their own way, CH presenting factual information and research findings, while DM spoke about her own experience and that of other people with learning disabilities who are known to her, which raised some of the following issues:

- Difficulties with understanding:

I have a lot of problems in trying to understand questions. I have problems in understanding what someone's trying to explain to me ... not every time.... and then I have problems with words that I really don't know what they mean. I have problems in trying to get people to understand what I'm trying to say... which causes me to get upset and then frustrated. (DM)

- "Covering up" difficulties/finding ways round them:

I think because all throughout my life I've managed to sort of bluff my way through life, I've sort of bluffed my way through everything else, you know, if someone asks me, I don't know, maybe some question that I don't really understand, I may try and turn it round to a different way..... (DM)

- Learning disabilities compounding emotional and mental health difficulties:

The learning difficulties does actually add ... it does add to, like when you get depressed and that, because when you're depressed and you're feeling sort of worthless and that, and everything kicks in at the same time, you know, "You can't do nothing", and "You're thick" and you know, all that kicks in. (DM).

- Painful life experiences adding to the difficulties:

In my case I had a very hard upbringing, so therefore I was always told how thick I was. How stupid I was. I got no common sense etc, then you start to believe all these things. It goes out in the street and people start taking the mickey out of you etc. and then you.... by this time you really believe you can't do anything and the depression sets in. (DM)

DM also invited participants to take part in a play she had written about the experiences of being misunderstood, devalued but finally appropriately helped in the context of her experiences of schooling. The play was divided into some short scenes with teachers who were not helpful in different ways, and some scenes at the end where a teacher did help and support her. DM notes:

We also did a play that I wrote ... and they enjoyed that, because that play is actually a true life, it's something that I went through.....My aims were actually thinking that it was a good opportunity for me to help change the way that people think and help them...for the future really.....hoping that they could learn a lot out of it and see where the mistakes were that have been done and what could be done now to put things right...The mistakes were sort of like teachers not picking up on things that were happening, not realising that I had this learning difficulty and just accusing me of being stupid....common for people to say "so thick. (DM)

The question about adapting CBT for people with learning disabilities was dealt with by CH, making use of research literature about this issue (e.g. Stenfert-Kroese, Dagnan and Loumidis 1997) and information about employment and learning disabilities was researched and presented by an honorary assistant psychologist (KD). The session ended with an exercise devised by the facilitator with a learning disability (DM) in which she provided direct consultation to small groups who were considering how they would work in relation to a particular difficulty: She notes:

It was something that I came up with and ... I went around each table ... the people that I was talking to that day, were people that were training to help people with learning difficulties on the phone with mental health problems as well. So, I was giving them a hard time to see how they would cope if somebody did phone them, and how I done it was... this was all an act, so I pretended to be a person who had a support worker, the support worker got me a job, but I lost the job because I didn't know the days of the week, and I was supposed to have started maybe on a Monday, but I didn't turn up till Wednesday, and I wanted to know that now that I've lost the support worker, how were they going to help me learn the days of the week, and when I should be at work, and when I didn't have to be got to work. And I really did give them a hard time, a very hard time, because I kept coming up with different questions each table I went to. (DM).

(I wanted to get through).....how frustrating it can be for somebody, especially if they have got a mental health problem at the same time, I wanted to get through that they may have to ask the same question, but in like three different ways before somebody understood it. I wanted to get through that life can be really difficult. I also wanted to get through to them that certain ways could help people in the future, by giving them my feedback on what they just said. (DM)

I gave them all the same question. But each time I went round to the table I think I may have added something to make it harder. I think, you know, one table I said, about "I had a support worker", second table, I sort of said, "well, I don't understand", one of them was ... going to help with maybe a calendar that had different kinds of fairies on ... each different coloured fairy represented a day of the week, so then I would give them a harder question, by saying, "I don't know my colours", and it got really really hard....."I can't read, so I can't read your calendar"....."I'm not eating because I've got no money, so worry takes over"... "If I do get a job interview and that how could they help me with this?"... I think a lot of them would have passed the test. (DM)

The reason I done it was because I 'm not as bad as some people out there. I am bad with learning difficulties, but there are people worse than me, and I wanted to do this because they would come up against people ... like the questions I was giving them. And I wanted to see for myself how they would handle that. (DM)

Evaluation of the Joint Training

The practitioners were given questionnaires before and after the session, and asked to provide pseudonyms to allow for the matching of forms. They were asked about their previous personal and professional contact with people with learning disabilities, and to complete brief Likert scales covering knowledge about, and confidence in, working with people who have learning disabilities. These scales were taken from the work of Manners and Burns (2008), who evaluated a teaching block for medical students, creating their own scales after having identified some difficulties with the use of existing scales for their purposes. The scales were slightly adapted, in line with changes suggested by the authors when critically reviewing their work. Prior to and after the session, practitioners were asked to choose a response to the following statements "I feel I know about learning disabilities" (on a 5 point scale from "very little to "a great deal") and "I feel confident about working with a person who has a learning disability" (on a 5 point scale from "not at all" to "fully confident"). They were also asked to offer explanations for any increase in knowledge or confidence after the event.

Results: - Contact with People with Learning Disabilities Prior to the Training Session

Thirty two practitioners attended the training day and completed pre and post evaluation forms, (although it was only possible to match 24 of these where the pseudonyms remained clearly the same). Sixty two per cent had some previous contact with people with learning disabilities, and 56 per cent had worked with them in a professional context.

Results: - Rated Knowledge About People with Learning Disabilities Before and After the Training Session

A Wilcoxon Signed Ranks test was used to compare practitioners' ratings of knowledge before and after the session. The results showed a significant increase in rated knowledge, $z = -3.50$, $p < 0.05$. In answer to a direct question about whether their knowledge had increased as a result of the session, all the participants except one answered "Yes". The reasons spontaneously provided can be grouped as follows, according to frequency of times that they were mentioned by participants:

- Contact with and learning from the facilitator with learning disabilities, mentioned by 59 per cent ($n=19$) of the group. Participants said they had valued hearing her experiences,

meeting and talking to her, observing the play that she had written and gaining her direct advice to them in the context of the exercise about their work.

- Understanding more about learning disabilities, mentioned by 34 per cent (n=11) of the group. Participants highlighted knowledge about the life experiences of people with learning disabilities, different ways in which things can be confusing, how people may try to hide their difficulties, how frustrating it can be not to be understood, and learning about experiences people may have had in the past when there was less general awareness about the needs of people with learning disabilities.
- Gaining information about how to work with people with learning disabilities, mentioned by 28 per cent (n=9) of the group. This included learning how to begin work, how to broach the subject of a person's learning disability, suggestions about ways to adapt communication, how visual aids can make CBT more accessible, the use of simpler language and trying to keep one idea in each sentence.

Results: - Rated Confidence about Working with People with Learning Disabilities Before and After the Training Session

A Wilcoxon Signed Ranks test was again used to compare ratings of confidence before and after the session. The results showed that there was a significant increase in felt confidence, $z = -3.66$, $p < 0.05$. All the participants except five answered "Yes" to a question about whether their confidence had increased as a result of the session. The reasons spontaneously provided for this can be divided into similar areas to those mentioned above, but the frequency with which these were mentioned was different:

- Gaining information about how to work with people with learning disabilities, mentioned by 59 per cent (n=19) of the group. Items mentioned included looking at practical tools to give to clients, how to ask sensitive questions, the importance of checking understanding with clients, things that might need to be different, working with clients at their pace and thinking about how to address real problems.
- Contact with and learning from the facilitator with learning disabilities, mentioned by 16 per cent (n=5) of the group.
- Understanding more about learning disabilities, also mentioned by 16 per cent (n=5) of the group. Items mentioned included learning that it is acceptable to ask and be honest about not knowing what might be difficult for a person with learning disabilities and the many potential different needs associated with disabilities.
- One person mentioned "learning more about employment support", and another noted that "it is ok to try and not just refer on".

Discussion

This was clearly a single training session with a very small group of mental health workers, over half of whom had already had contact with people with learning disabilities, but the rating scales did indicate an increase in feelings of knowledge and confidence in relation to people with learning disabilities after the teaching session. Interestingly, there was a suggestion that participants attributed the increase in their knowledge principally to the opportunity to have contact with someone with experience of learning disability and mental health services, while the principal reason given for increase in confidence was gaining greater knowledge about how to do their job.

These findings do add to the body of knowledge supporting the usefulness of learning from people with learning disabilities as trainers. The training session would appear to have had elements of the optimal conditions of contact noted by Allport (1954) in that the trainer with learning disabilities had equal status to both the other trainer and the trainees, shared the common goal of contributing to their learning, was not in a situation of competition, and the contact was sanctioned by the higher authority of the institution. Tracy and Iacono (2008) note, however, that it is difficult to evaluate whether improved ratings after a short course reflect altered immediate perceptions or significant change which would additionally be reflected in enhanced practice.

A limitation of the evaluation form was that participants were not asked to provide further information where they indicated that they did not feel their confidence or knowledge had increased. However, one person left the comment:

Aware of lots of difficulties within our role. Aware of what should do, but unsure if it will always be possible.

Another person noted that she had learnt:

That it is not as scary in practice as the image of trying to support someone with LD.

It would be interesting to explore further such fearful images and perceived role limitations to see if there might be ways to impact helpfully on these.

It would also have been useful to have found out more about the Psychological Wellbeing Practitioners themselves and factors which could have influenced their perceptions of the training session, such as their individual ages, previous experience or professional backgrounds. Additionally, it would be interesting to make further contact with them, to gain a perspective on the potential impact of the training on their subsequent practice, and other factors which may have contributed to any subsequent increase in knowledge and confidence in working with people who have learning disabilities.

General Conclusions

The Psychological Wellbeing Practitioners who participated in this training session appear to have appreciated and benefited from direct contact with a trainer with learning disabilities. Given that these workers are a subset of generic mental health workers this adds to research suggesting that such contact can be helpful in enhancing knowledge and confidence more generally. The contribution of the service user with learning disabilities included making use of drama to help students understand painful life experiences, and providing direct feedback on the extent to which their communication and therapeutic skills might need to be altered to meet the needs of people with learning disabilities, and these exercises were appreciated by participants.

There would appear to be a need to continue to explore the contribution that people with learning disabilities are able to make to training, including those with varying levels of intellectual disability. This could include using qualitative research methodology to further investigate the experiences and ideas of those who are already training, finding ways to involve new trainers (providing them with appropriate preparation and support), discovering more about the issues people with learning disabilities consider important to train health professionals about, and incorporating the views of the carers of those who have more significant impairments. It also seems potentially useful to document experiences of the realities of joint training to share information about this can work optimally.

Closing Observations from the Facilitators

Practicalities of Planning the Joint Training

When we...talk about what's going to happen, things normally pop in my head, and then me and CH will sort certain things out.....The question times are quite good, but they can be hard as well, but I've got a choice. If I don't want to answer that question, I just say, "I really would rather not answer that one". But that hasn't happened yet. (DM)

We meet to discuss a teaching session, I write up our notes and we then check it through again, at which point DM often has new ideas and suggestions. It seems to work when we find a question that we can both answer in our different ways – like 'what is a learning disability?' It also feels important for DM to contribute to formal presentations of information, so that we share the role of information-giver, as well as contributing her experience. We've made an agreement that we have both signed about the work we do, how often we meet and the work we have planned for the future. (CH)

Learning from the Joint Training

It was very nervous at first and I think I get nervous every time I do work alongside CH.....but at the same time, I'm always thinking, "This has got to be a help to others", and in a funny way, I sort of enjoy it as well, even though the nerves kick in.....but once I know that they're nerves, then I'm fine and it gets to point where they can't shut me up!.....The confidence, that's the biggest thing. Yeah I believe I have got more clever.....It's sort of, because it's built my confidence it's sort of give me that pathway to think 'uh okay maybe I couldn't have done that before but I've done this, done this (teaching) so lets go for that (new thing). (DM)

I have been conscious of potential difficulties, and have learned a lot from DM telling me when I do things too quickly, don't make enough sense or appear to expect that we will respond to the needs of learning in the moment, which I am aware can be anxiety provoking. I have been concerned to try to ensure that the demands of training have not been stressful or impacted adversely on her mental health, but have been consistently reassured that this has not been the case. I have learned an enormous amount from her personal ability to consider the needs of other people with learning disabilities and devise creative and helpful tools to meet the needs of learners, which have been appreciated in a number of training sessions. Her contributions match the knowledge and findings of the literature and bring them to life. (CH)

Final Thoughts

It was really serendipitous to discover that a member of our existing service user advisory group had experience of learning disabilities and was able to take on the challenges of training. (CH)

(The students came) up to me afterwards and sort of "Thank you so much for that, we learnt a lot". And that to me is very important that they've actually learned something....from that day...and it just makes you go home, quite proud. (DM)

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